

***Preliminary Draft***

**Transplant Services**

**Of**

**Chronic/Long Term Care Chapter**

**District of Columbia  
State Health Systems Plan**

**State Health Planning and  
Development Agency  
District of Columbia  
Department of Health**

**TRANSPLANT SERVICES**

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### TRANSPLANTATION SERVICES

#### I. INTRODUCTION

Organ transplantation has grown as an important medical service for the treatment of end stage organ failure and accepted as an intervention for selected patients whose other option is either mechanical/artificial support or death. The diagnostic services are highly specialized, and the cost of staffing and equipping these specialized services is expensive.

The advent of immunosuppressant pharmaceuticals in the early 1980s and the development of a federal organ procurement and transplantation network, a national system regulating transplantation and donor organ allocation, currently run under government contract by the United Network for Organ Sharing (UNOS), have enhanced transplantation services (a brief history of organ transplants is enclosed in the Appendix, Table A-1) and the incredible growth in the number of patients awaiting transplants may be due largely to the success of transplantation. For virtually all types of transplants performed, the one-year patient survival rate is 80 percent or higher, and long-term survival rates have increased dramatically. Some people have already survived 30 years or longer with transplanted organs, and that experience will become much more common as surgical and medical techniques improve.

The most common organs that are transplanted include kidney, heart, liver, lung, pancreas, and small intestine. Other tissues of the body that may also be considered within the realm of transplants are cornea, skin, bone, heart valves, bone marrow, stem cells, larynx, and limbs such as hands. The primary sources for organ donation are either deceased or live donors. Deceased organ donations account for 100 percent of all organ donations for heart, lung, pancreas, and intestine transplant as well as a significant portion of kidney; however, live donations account for an increasing percentage of kidney and liver transplants.

This chapter will focus on the background and history of organ transplants, including the establishment of the national and regional organ transplantation organizations that facilitate donation and transplant services, review types of transplant programs, and provide a discussion of issues related to transplantation. The middle sections identify the transplant centers, discuss the number of transplants performed, and project future need for services. Finally, standards and criteria will be discussed, as will goals and recommendations for transplant services in the District. Of note, this chapter has a more regional approach than several of the other service delivery chapters because of the regional organization of the transplant and organ recovery system structure.

### **II. BACKGROUND AND TRENDS**

#### **A. Organization of the National Transplant System**

In 1984, the passage of the National Organ Transplant Act created a national transplant system to be operated by transplant professionals with oversight by the U.S. Department of Health and Human Services (HHS) in order to ensure an equitable distribution system. This federal law authorizes the Secretary of HHS, by contract, to establish and operate an organ procurement and transplantation network (OPTN), which must be a private entity operated in the private sector. UNOS, the contracted OPTN since 1984, is responsible for the following:

- Managing the national transplant waiting list and matching donors to recipients 24 hours a day, 365 days a year;
- Monitoring every organ match to ensure adherence to UNOS policy;
- Working with UNOS members to develop equitable policies that maximize the limited supply of organs and give all patients a fair chance at receiving the organ they need, regardless of age, sex, race, lifestyle, or financial or social status; and,
- Setting professional standards for efficiency and quality patient care.

The UNOS system consists of more than 50 independent or hospital based non-profit organ procurement organizations (OPOs) that have exclusive defined service areas in which they promote organ donation and allocated donated organs. Service areas range in geographic territory from a few counties to multistate areas, and in population from 700,000 to 11 million people. The OPO is required to have a working arrangement with all of the hospitals in the service area, including those that house the transplant programs. OPOs evaluate potential donors, discuss donations with family members, and arrange for the surgical removal of donated organs. OPOs are also responsible for preserving organs and arranging for their distribution according to national organ sharing policies.

The Washington, D.C., metropolitan area is served by the OPO #11, the Washington Regional Transplant Consortium (WRTC), with offices in Falls Church, Virginia. The service area for WRTC includes the District of Columbia; Montgomery, Prince George's and Charles counties in Maryland; and 11 jurisdictions in Northern Virginia. Northern Virginia jurisdictions include Loudoun County, Falls Church City, Fairfax County, Fairfax City, Arlington County, Alexandria City, Manassas City, Manassas Park City, Fauquier County, Prince William County, and Stafford County. The 2000 census number for WRTC's service area population is approximately 3.8 million persons.

### **B. Allocation Process**

UNOS bases allocation policies upon a set of principles that seek to balance several ethical and clinical considerations. Equitable organ allocation policy is defined as those rules, which balance with one another, to accomplish the following:

- Enhance overall availability of transplantable organs;
- Allocate organs based upon medical criteria, striving to give equal consideration to medical utility (i.e., net medical benefit to all transplant patients as a group) and justice (i.e., equity in distribution of both benefits and burdens among all transplant patients);
- Provide transplant candidates reasonable opportunities to be considered for organ offers within comparable time periods, taking into consideration similarities and dissimilarities in medical circumstances as well as technical and logistical factors in organ distribution; and,
- Respect the autonomy of persons.

A fundamental requirement of the federal law is that organs be allocated to patients based upon medical criteria, not social criteria or economic status, nor can they be allocated to transplant centers that then choose the most appropriate patient.

The majority of the transplant community believes that local allocation enhances local organ procurement. Therefore, from an operating perspective, deceased donor organs are allocated to the first person awaiting transplantation at transplant centers located within the local area (usually defined as within the procuring OPO) for which there is a medical match. One exception to this general rule is a six-antigen match kidney (considered a perfect match kidney) that must first be offered to any patient nationally that is determined to be a six-antigen match by histocompatibility testing. The other exception to this rule is livers, which are first allocated to patients within the UNOS designated region that are seriously ill and will die within a few days without the transplant. If local organ allocation is not possible, and the organ is a kidney, pancreas, liver, or intestine, it is offered within the UNOS OPO designated region. There are 11 regions in the country whose boundaries generally, although not always, follow state boundaries and serve areas with a population ranging from fewer than 10 to more than 40 million; the District is part of UNOS Region 2. Finally, if there is no match locally or regionally, organs are offered nationally.

Thoracic organs that cannot be placed within the local area are distributed according to a different arrangement to avoid unacceptable ischemic time. The distribution unit is a circle that has a radius from the OPO of 500 miles, which is the distance that can be covered by a private jet in two hours. If not accepted within that circle, the organ will be offered via successive concentric 500-mile circles.

## C. Significant Issues and Problems

### 1. *Shortage of Available Organs*

The single most important issue in organ transplantation is the disparity between utilization and potential demand. This is expressed by the ever-expanding list of potential recipients awaiting transplantation and the number of deaths while on the waiting list.

**Although there has been an increase in the number of transplants performed, the demand has increased exponentially and the waiting list grows nationally by about 5,000 people per year.**

The supply of donor organs has grown by only a few hundred per year. Constrained utilization and increased waiting times result in an increasing number of deaths of those individuals on a waiting list. It is also important to note that the waiting list numbers may represent an undercount because people either withdraw from the waiting list or do not join the waiting list because the low supply of organs is discouraging. If the supply could be increased, the waiting list may continue to significantly outpace the supply.

Nationally, as of April 2002, there were 7,857 people waiting for an organ transplant. During calendar year 2002, there were only 2,848 transplants according to UNOS. As of April 2002 there were 133 Washington, D.C., regional (local) area patients awaiting organ transplant, but locally there were only 275 deceased donor organ transplants in 2002. Table 1 lists the national and local area patient waiting list by organ as of April 2002.

**Table 1. National and Local Patient Waiting List by Organ – June 2001**

	National Waiting List	Local Waiting List
Heart	4,148	25
Heart-Lung	212	1
Intestine	192	Not available in WRTC area
Kidney	52,216	1,573
Kidney-Pancreas	2,540	111
Liver	17,546	321
Lung	3,821	30
Pancreas	1,317	57
Pancreas Islet cells	295	1
<b>Total*</b>	<b>79,857</b>	<b>2,133</b>

\* Some patients are waiting for more than one organ; therefore, the total number of patients is less than the sum of patients waiting for each organ.

Source: Washington Regional Transplant Consortium, June 2001

### **2. *Additional Barriers to Organ Donation and Transplantation***

Multiple factors influence organ transplantation services. In addition to the existence of a waiting list for organs, availability of organs, and number of transplants performed, the other factors that impact transplantation services include reimbursement for services; race, ethnic, and religious beliefs; diagnosis; and the availability of support services pre- and post-transplantation.

#### *a. Financial constraints*

The costs associated with transplantation extend beyond the surgical procedure and include non-medical costs. Although commercial and federal health insurance programs pay for some organ transplantation and related hospital and medical costs, many of the non-medical and pharmaceutical costs are not reimbursed. Although patients seek other avenues for long-term financial support, finding the resources is not always possible.

#### *b. Social support systems*

The support systems required for organ transplantation involve the availability of family or a caregiver to assist in a variety of services, including assistance with activities of daily living, medication administration, transportation, household chores, child care services, and others.

#### *c. Lack of outreach for organ and tissue donation by medical community*

WRTC reports that there are 3.8 million people in the service area and yet in 2002 only 87 people died and donated organs, and 201 people died and donated tissues. Lack of funds for comprehensive community outreach, public awareness, and the manner and timing of hospital requests for organ and tissue donation are reasons cited for lack of organ donation in the District and surrounding area. (See Appendix Table A-3 for a list of organ donors by area hospitals.) The WRTC 2002 OPO data report noted that when the patient's family was approached about organ donation, the rate of consent for donation by physicians was 26 percent in 2002 and 11 percent in 2001, whereas the rate of consent for donation when WRTC personnel discuss the donation option was 58 percent in 2001 and 63 percent in 2002.

### **3. *Programs Designed to Increase Donors***

#### *a. National Minority Organ Tissue Transplant Education Program (MOTTEP)*

Since June 1991, the National Minority Organ Tissue Transplant Education Program (MOTTEP) has been working to address the shortage of donors. National MOTTEP began addressing the problem within the African American/Black population in 1978 when data indicated that while 70 percent of African Americans were on dialysis, only 3 percent were donors. Two focus groups of 40 African Americans within the District of Columbia were convened and they discovered the five reasons for reluctance to donation:

(1) lack of transplant awareness, (2) religious beliefs, (3) fear of premature death (being declared dead prematurely), (4) distrust of the medical community, and (5) racism.

Armed with this information, presentations were made to the community as well as a media tour to 50 cities. The number of African Americans signing donor cards, having family discussions, and becoming donors increased as a result. It was proven that face-to-face dialogue with transplant recipients, donors, and donor family members was the ideal remedy for this problem. Therefore, in 1991, the Washington, D.C.-based National MOTTEP came into existence, which applies the same methodology to all minority populations (Hispanics, Asians, Pacific Islanders, Native Americans, and Alaska Natives) by using culturally sensitive and ethnically similar persons as key messengers.

In 1993, National MOTTEP received a two-year contract to develop a strategic plan and implement programs within 11 cities across the country. In 1995, National MOTTEP received a five-year grant from the National Institutes of Health to implement the program within 15 major cities, including Washington, D.C. The grant also allowed National MOTTEP to add a prevention component focusing primarily on diabetes, hypertension, alcohol and substance abuse, and nutrition and exercise.

All of MOTTEP's sites are working with local beauty salons, barber shops, shopping malls, schools, and other community organizations to ensure that everyone receives vital information that can ultimately save lives and prevent the need for transplantation.

### *b. Gift of Life Donation Initiative*

In April 2001 the U.S. Department of Health and Human Services launched a program to increase vital donations of organs and tissues among Americans. The Gift of Life Donation Initiative encourages organ, blood, and tissue donation as well as registration for bone marrow donation. The initiative includes a new national Workplace Partnership for Life campaign, in which employers, unions, and other employee groups will join in a nationwide network to promote donation. It also involves creating donor education programs in drivers' education programs and donor cards, which would specify tissues to be donated.

### *c. The Washington Regional Living Donor Registry*

Through WRTC, a pilot program called the Washington Regional Living Donor Registry was established that offers individuals the opportunity to donate a kidney to a patient on the waiting list. To increase the pool of living kidney donors, living donors may elect to give kidneys to medically incompatible friends or relatives through a living donor registry. Living donors are encouraged to give kidney transplants because the success rate is better than deceased donor kidneys and the waiting time is shorter. The living donor may designate a relative or friend for the donation. In the event that the donor's blood or tissue type do not match those of the designated patient, the kidney will match with another patient on the local waiting list. This allows the relative or friend of the



living donor to move up on the waiting list to receive the next deceased donor kidney for which they are compatible and also removes one person from the local waiting list. A living donor may also offer to donate a kidney to the list of waiting patients with no specific recipient. The kidney is then allocated locally according to UNOS rules. In addition to meeting medical requirements for live donation of an organ, the donor must undergo extensive psychological evaluation, whether he or she is known to the patient or not, prior to that candidate being accepted for the program.

### **D. EMERGING TECHNOLOGIES**

#### **1. *Stem Cells Transplants***

Stem cells are obtained from living adult human tissue or from developing embryos, and they hold the promise of treating illnesses, such as Alzheimer's or Parkinson's disease. Embryonic stem cells come from in vitro fertilization, which fuse sperm with eggs in a petri dish, and not from aborted fetuses (defined as embryos older than nine weeks). Most adult stem cells are primed to develop into the same type of tissue from which they are originally taken: liver tissue generates liver tissue, skin cells generate additional skin cells, and so on. There is some evidence that adult stem cells can be made to change into other types of tissue; this research is continuing to demonstrate the possibilities of the technique. Tissue taken from embryos, however, has clearly been shown to be able to develop into a wide range of tissues. It is believed that these cells can develop into almost any tissue type and could be enlisted to treat a number of diseases. Examples include transformation into islet cells in order to restore function to the pancreas of a person with diabetes; morphing into nerve cells in order to replace neuronal tissue damaged by strokes, spinal cord injuries, Alzheimer's, and Parkinson's diseases; or developing into skin tissue to provide skin for a burn victim.

The stem cells may play a major role in supporting organ transplantation services by decreasing the number of people on the waiting list for a specific organ. For example, infusion of stem cells into a patient's liver could produce new liver cells, rejuvenating an organ that is decimated by hepatitis or cirrhosis. As of June 2001 no federal grants had been awarded for studies using human embryonic stem cells; however, there are several privately funded research projects in place. It is believed that human clinical trials involving the infusion of embryonic stem cells are not likely to take place before 2004.

#### **2. *Islet Cells Transplants***

The American Diabetes Association's 60th Annual Scientific Sessions (June 2001) report included the status of islet cells transplantation. The report stated that scientists have developed the first human beta cell line that responds to glucose stimulation by secreting insulin, both in the test tube and when transplanted into laboratory animals. This technique could provide a vast pool of cells for curing people with diabetes. If it is

possible to use human beta cell lines as an unlimited source of cells for transplantation into people with diabetes, it could significantly address the organ shortage.

Islet cells transplantation could affect the more than 16 million Americans with diabetes. Diabetes can lead to severely debilitating or fatal complications, such as blindness, kidney disease, heart disease, and amputations. It is the sixth leading cause of death by disease in the United States and the seventh leading cause of death in the District. It is expected that the first candidates for transplantation would be people with type I diabetes (formerly called insulin-dependent or juvenile diabetes). Type I diabetes is usually an autoimmune disorder in which the body destroys the insulin-producing beta cells in the pancreas and it typically starts in children or young adults with a slim body type. With an unlimited supply of islet cells, transplantation also could be extended to help people with type II diabetes (formerly called non-insulin-dependent or adult-onset diabetes). Type II usually arises because of insulin resistance—cases in which the body fails to use insulin properly—combined with relative (rather than absolute) insulin deficiency. In other cases, it primarily involves an insulin secretory defect, combined with some insulin resistance. It typically occurs in persons who are over 45 and are overweight.

Islet cells transplantation issues that will be addressed in the next couple of years include the following: innovative use of immunosuppressive drugs to decrease the destruction of islet cells from immunosuppressant drugs such as prednisone; the donation to patients of both islet and pancreatic stem cells from the same adult cadaver to help prevent rejection without immunosuppressive drugs; and the exploration of genetic engineering techniques to deliver other proteins that might interfere with the rejection process.

The Immune Tolerance Network, a consortium of 10 transplant centers across the country, will be further evaluating islet cell transplantation in 40 patients in the year ahead.

### **3. *Artificial Organ Transplants***

Artificial organs are devices that are designed to replace normal body functions that have been lost due to disease or injury. Artificial organs may be implanted or used outside of the body. They may permanently replace the body's function, or they may be temporary until a suitable living organ can be transplanted. When irreversible organ damage occurs, the best long-term solution is usually transplantation. Given the limited supply of living organs, artificial organs provide an alternative to simply waiting for an organ to become available. Some artificial organs, such as the artificial kidney or hemodialysis, can be a temporary measure to maintain as normal a life possible, while others, such as the heart-lung machine, are required to preserve life. Lung machines include ventilators—mechanical devices that provide oxygenated, volume-controlled air and support life. Currently, there are no artificial organs available to replace functions of the pancreas, intestine, or liver.

In July 2001 surgeons at Jewish Hospital in Louisville, Kentucky, transplanted the first self-contained, titanium-and-plastic mechanical heart replacement in a 50-year-old male with the hope of extending the patient's life only a month or so. The device, known as AbioCor, is designed to allow recipients to maintain a productive lifestyle while wearing it. It is considered a technological leap from earlier mechanical hearts. Power is sent from a battery pack worn outside the body through the skin to an implanted coil, control package, and backup battery. The internal battery can maintain a charge about 30 minutes. Selection criteria for this trial include patients suffering from a chronic, progressive heart disease expected to result in death within 30 days and those ineligible for receiving a human heart transplant.

Artificial hearts used experimentally in the 1980s were different from the AbioCor in that they were attached by wires and tubes to machinery outside the body. The longest survival rate for previous artificial hearts was 620 days.

#### ***4. Animal Transplants/Xenotransplants***

The transplantation of animal organs remains experimental although there have been several attempts to replace human organs with animal organs, such as a baboon heart implanted in a baby. These “xenotransplants” stir extensive controversy among ethicists, medical professionals, and the public.

### **III. SUMMARY RESOURCE INVENTORY AND HISTORICAL UTILIZATION OF SERVICES**

#### **A. Summary of Transplant Centers**

##### ***1. Solid Organ Transplant Centers***

Table 2 identifies those centers in the WRTC that perform transplants.

##### ***2. Intestine/Small Bowel Transplant***

There are no intestine/small bowel transplant centers in the WRTC service area. The nearest transplant centers for intestine/small bowel transplants are Johns Hopkins Medical Center (in Maryland) and the University of Pittsburgh Hospital (in western Pennsylvania). In 1999, the University of Pittsburgh Medical Center performed eight transplants. There were two patients on the Johns Hopkins Hospital Medical Center waiting list at that time. Nationally, in May 2003 there were 181 on the intestinal transplant waiting list.

##### ***3. Stem Cell/Bone Marrow Services***

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Three hospitals in the WRTC have the capacity for stem cell/bone marrow transplantation services. They are the Children's National Medical Center (Autologous marrow and peripheral blood progenitor cell transplantation, including collection and laboratory processing), Georgetown University Hospital, and the National Institutes of Health (District of Columbia Hospital self-report: July 2001).

The Foundation for the Accreditation of Hematopoietic Cell Therapy (FAHCT) is a nonprofit corporation developed by the International Society of Hematotherapy and Graft Engineering and the American Society of Blood and Marrow Transplantation for the purposes of self-assessment and accreditation in the field of hematopoietic cell therapy. FAHCT has established standards for the provision of quality medical and laboratory practice in hematopoietic cell transplantation. It conducts inspections, accredits programs that will encourage health institutions and facilities performing hematopoietic cell transplantation to voluntarily meet these standards, and recognizes compliance with standards by issuing certificates of accreditation.

Table 2 summarizes the facilities within the WRTC area that offer accreditation and/or current capacity to provide services as of May 2003.

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**Table 2. Types of Active Organ Transplantation Program in the WRTC Service Area, May 2003**

<b>Organ</b>	<b>Children's National Medical Center</b>	<b>Georgetown University Medical Center</b>	<b>Howard University Hospital</b>	<b>INOVA Fairfax Hospital</b>
Heart	Yes			Yes
Intestine				
Kidney	Yes	Yes	Yes	Yes
Liver		Yes		Yes
Lung				Yes
Pancreas		Yes		Yes
Heart/Lung				Yes
Kidney/Pancreas		Yes	Yes	Yes

<b>Organ</b>	<b>National Institutes of Health</b>	<b>Walter Reed Army Medical Center</b>	<b>Washington Hospital Center</b>
Heart			Yes
Intestine			
Kidney	Yes	Yes	Yes
Liver		Yes	
Lung			
Pancreas	Yes (Islet Cells)	Yes	Yes
Heart/Lung			
Kidney/Pancreas	Yes	Yes	Yes

Source: WRTC, May 2003

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Table 3 shows the national number and status of FAHCT-accredited programs as of August 2001.

**Table 3. Number and Status of FAHCT-Accredited Programs, August 2001**

<b>Program Status</b>	<b>Number</b>
Facilities Registered	197
Facilities Accredited	83
Inspected Facilities with Accreditation Pending	55
Inspections in Process	11
Facilities Completing Checklists	48
Inspectors Trained	306

Source: University of Nebraska Medical Center website:  
<http://www.unmc.edu/Community/fahct/Default.htm>

**Table 4. FAHCT-Accredited Facilities, 2001**

<b>Facility</b>	<b>Program Accredited to Perform</b>
Holy Cross Hospital Silver Spring, MD	Autologous peripheral blood progenitor cell transplantation, including collection and laboratory processing
The Cancer Center of Providence Hospital, Washington, DC	Autologous peripheral blood progenitor cell transplantation, including collection and laboratory processing
Walter Reed Army Medical Center Washington, DC	Autologous peripheral blood progenitor cell transplantation, including collection and laboratory processing
INOVA Fairfax Hospital Bone Marrow Transplant Program Falls Church, VA	Autologous marrow and peripheral blood progenitor cell transplantation, including collection and laboratory processing

Source: FAHCT website: [www.unmc.edu/Community/fahct](http://www.unmc.edu/Community/fahct)

### **B. Historical Utilization**

Table 5 identifies the number of organ transplants performed in D.C. hospitals.

### **C. Recovery and Importation of Organs**

In addition to observing the number of transplants performed, another important consideration is the number of organs recovered in the region. In 2002, a total of 378 organs from 87 donors were recovered. During the same year, 234 organs from local donors were transplanted in the WRTC service area (121 were performed at District transplant centers, 113 were performed at INOVA Fairfax Hospital) and 72 organs were exported to other areas. The remainder were either recovered for research or discarded

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due to medical unsuitability. The WRTC also imported a significant number of organs for transplant consideration. In 2002, of the 57 accepted imported organs, 40 were transplanted locally.

All totaled, the number of organs recovered within the area and imported from other regions is far less than the number needed by the 2,133 individuals reported to be on the local waiting lists.

The appendix at the end of this chapter provides a list of import referrals by organ type for 2001 and 2002 as well as a list of area hospitals that participated in organ and tissue retrieval.

**Table 5. Number of Living and Deceased Donor Organ Transplants in the District of Columbia  
1999 – 2002**

Year of Transplant						Total
	1998	1999	2000	2001	2002	
ORGAN	Number	Number	Number	Number	Number	
Heart	12	10	7	5	5	39
Heart/Lung	-	-	-	-	-	0
Kidney	205	225	135	192	197	954
Liver	14	32	26	46	51	169
Lung	-	-	-	-	-	0
Pancreas	7	3	1	4	6	21
Intestine	-	-	-	-	-	0
Kidney/ Pancreas	-	-	-	13	12	25
<b>Totals</b>	<b>238</b>	<b>270</b>	<b>169</b>	<b>260</b>	<b>271</b>	<b>1,208</b>

Source: UNOS critical data: transplants by state

Note: The only lung and heart/lung programs available in the WRTC service area are at INOVA Fairfax Hospital.

### IV. PROJECTIONS

The development of a model to predict the need for service capacity related to the performance of transplant procedures is associated with several unique challenges. First, the conditions that require transplantation are not themselves easily predicted or quantifiable. Second, the capacity to perform transplant and the opportunity to do the procedure are not related to one another. In every case an organ must be available. And, as noted in this chapter, organs are in very short supply. Therefore, this section will

focus on building an understanding of the factors that indicate need and making conclusions about future trends, based upon current conditions and past experience.

The need for transplants can be discussed if not quantified. Three dimensions of need are described here: incidence and prevalence of related diseases, population, and race.

### **A. Incidence and Prevalence of Related Diseases**

First, it is important to address the medical conditions that give rise to the medical necessity for organ transplant. Several trends are observed in section II of this chapter that point to increasing need; for example, the generally poor health status of District residents and the incidence per 100,000 population of deaths due to heart disease, diabetes, and chronic obstructive pulmonary disease (see Table 6) indicate a growing need for transplantation services for District residents. The following examples may demonstrate an emerging need:

#### Heart Transplants

Using the 1998 heart disease death statistics (291 per 100,000 population) and the U.S. Census data for the year 2000, an estimated 1,658 District residents are likely to have end stage heart failure.

#### Pancreas/Islet Cell Transplants

The incidence of type I or type II diabetes is an indicator of the need for pancreas or Islet cells transplant since a small number of affected patients may meet medical necessity criteria. The District rate for diabetes is 37.3 per 100,000 population and is increasing.

#### Kidney Transplants

The number of individuals on dialysis due to end stage renal disease is growing at an annual rate of 5.8 percent. It is logical to assume that the need for kidney transplants is related to this number. Therefore, it can be assumed that the need for kidney transplants is growing at a similar rate.

Since medical condition and not diagnosis determines the medical necessity for transplants, quantitative estimates of specific needs for transplants within a population cannot be predicted with any reliability. From these three examples alone, in addition to others described in this plan, the need for transplants is understood to be rising due to the incidence of disease.

### **B. Population**

The population of the District of Columbia is projected to grow from the 2000 U.S. Census count of 572,059 to 600,000 in 2010. To the extent that the need for transplants



is related to population growth, it will increase over this period in the District of Columbia, as well as throughout the Washington, D.C., metropolitan area (Metropolitan Washington Council of Governments (MWCOG), *Growth Trends to 2025*, summer 2000). Table 6 shows current population and growth for the District of Columbia over the period.

### C. Race

Given the current and projected population by race in the District of Columbia, it is important to address the barriers to access and cultural factors that affect the incidence of transplants for the African-American/Black category. The racial composition for the District is shown in Table 7.

These barriers suggest that while there is a higher need for transplants, the likelihood that procedures will be performed is lower, thus pointing to the need for public awareness in addition to patient and family education. To the extent that groups such as MOTEPP exist, as described in section II of this chapter, demand may increase at a rate higher than prevalence and population, if only because the barriers discussed below are reduced.

**Table 6. District of Columbia, Adjustment of Population Projection**

U.S. Census 2000	572,059
Estimated 2000 (based on 1990 census, MWCOG)	518,100
Projected 2005	523,500
Projected 2010	554,700
Average (mid-2007) of 2005 and 2010	539,100
Add adjustment for U.S. 2000 Census	53,959
<b>Revised Projected Population, 2007</b>	<b>593,059</b>
Rate of change, 2000 – 2007	0.0367

1. U.S. Census 2000 estimate from published data, U.S. Census website
2. MWCOG, *Growth Trends to 2025*, reports projections for total population for 5 year increments 2000 – 2025 based upon a range of vital statistics, as well as economic, socio-demographic and other trends
3. Average projected 2007 population is calculated by totaling 2005 and 2010 projections, and dividing by two.
4. 2007 Estimate Adjusted is the sum of the difference between MWCOG estimates for 2000 and actual US Census 2000 for each jurisdiction added to the Average Projected 2007 population.

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African Americans are less likely to be medically suitable for transplantation. According to a recent review of a random sample of 1,518 medical charts stratified by race, 9.8 percent of blacks, compared with 21.4 of whites, were considered medically appropriate for transplantation (Epstein et al., 2000). In the District, 23 percent were deemed medically unsuitable - slightly less than the 29.4 percent average for the network. The most common reasons for medical unsuitability among adults in the region were infections/HIV (15.9 percent), diabetes-related reasons (15.3 percent), cardiovascular disease (12.5 percent), noncompliance (10.1 percent), alcohol and other drug abuse (7.6 percent), and obesity (7.2 percent)

<b>Table 7. Distribution of Population Projection by Race</b>		
	<b>U.S. Census 2000</b>	<b>Projected 2007</b>
Black/African American	343,312	355,912
White	176,101	182,564
Asian/Islander	15,537	16,107
American Indian/Alaskan	1,713	1,776
Other	35,396	36,695
		593,054
1. Race as described in U.S. Census includes individuals of more than one race and those designating other. The number of individuals listed as other in this table includes both.		
2. Race is projected based on prorated share of U.S. Census 2000 population; held constant over the projection period. Growth rate for all is 3.67 percent over the period.		

Despite their higher rate of medical unsuitability, African Americans account for more than one-third of patients on the waiting listed for kidneys (UNOS, 2001b). There are many reasons for the over-representation of African Americans on the waiting list. As noted previously, there is a high prevalence of ESRD among minorities, particularly African Americans. Additionally, there is a shortage of minority donors, so that immunologic matching criteria result in more frequent donor matches for whites than for blacks (UNOS, 2000). In 2002, UNOS modified the kidney allocation criteria to eliminate some of the issues associated with immunologic matching and kidneys are now matched on blood type, patient waiting time and the DR antigen.

However, clinician bias also appears to be a factor in access to transplantation. Ayanian et al. (1999), found that 59.6 percent of African American women and 57.9 percent of African American men were referred for evaluation for kidney transplants, compared with 80.3 and 92.2 percent for white women and men, respectively. This study further found that 40.3 percent of black women and 40.6 percent of black men were placed on a waiting list or received a transplant, compared with 68.9 and 67.9 percent of white women and men, respectively. Racial differences in access remained significant even after the researchers controlled for coexisting illnesses, cause of renal failure, socio-demographic factors, and health status.

Finally, African Americans are less likely than whites to complete the transplantation process, once they are wait listed. Part of the problem, as mentioned, lies in the lack of immunologically compatible organs available for transplantation in African American/Blacks. A second reason is the lack of living donors; in the previously cited study by Epstein et al. (2000), 12.9 percent of whites versus 3.2 percent of African American/Blacks received transplants from living donors. Compliance issues also come into play, as failure to complete steps in the transplantation process may disqualify the patient (Alexander & Segal, 2001).

### **D. Capacity and Demand**

As mentioned at the outset of this section, projecting transplants must be related to supply and demand as much as to the need of a population for the service. The issue is considered here in several ways. First, the number of organs retrieved and the number of organs imported set a limit on availability that is well below the number of individuals awaiting organs. Taken altogether, as reported in section II, the number of organs imported and locally retrieved that were ultimately transplanted in the WRTC service area totaled just 274, compared with 2,133 patients on the area waiting list

Table 8 shows the waiting lists for calendar year 2000 and the volumes of service for transplant procedures for each organ at each center. This allows direct comparison of the met need, in terms of procedures performed and the immediate demand, with the waiting lists of individuals.

For most centers, volume of procedures is low while patient waiting lists remain high. This suggests that if more organs become available, there is more than sufficient service capacity in the current local programs to perform the needed procedures. Additionally, thresholds recommended by national organizations, in particular UNOS and Medicare, recommend higher volumes than are currently observed, as such no new centers for the District of Columbia. Only as the volume of donated organs increases to the point where these thresholds are reached will demand exceed capacity of the current system.

Only one area of solid organ transplant is not provided by WRTC centers, intestine/small bowel, and, therefore, the projected need for intestine/small bowel transplants is unknown for the D.C. metropolitan area. In the event a facility considers applying for a Certificate of Need (CON) to perform intestine/small bowel transplants, it is federally required that the facility will meet the UNOS criteria for the transplant program and will submit documentation that the program will be able to meet the annual minimum volume standards.

**There is more than adequate capacity to perform the transplants that will be demanded in the region over the period of the plan. For most centers and organ services, the numbers of procedures fall below industry standards. At the same time, demand for procedures is severely restricted by the availability of organs. Thus, while need is present and growing, requirements to add capacity are not evident.**

### **V. CRITERIA AND STANDARDS**

For the purposes of regulation under this chapter, transplantation refers to the surgical insertion of major replacement solid organs (kidney, liver, pancreas, heart, and lung), intestine or small bowel, hematopoietic stem cells, islet cells, and other transplantable cells. Because the ability to do one type of transplant does not translate to the ability to do any other type of transplant program, the D.C. Department of Health (DOH) requires a separate CON to be filed in order to develop any new transplant program whether or not the institution has another transplant program. In addition, hematopoietic stem cell transplant programs, both autologous and allogeneic, whether inpatient or outpatient, should be subject to CON review. This separate approval of transplant programs is consistent with the policies of the UNOS and FAHCT. Each agency reviews individual programs separately.

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<b>Table 8. Transplant Statistics by Center and Organ</b>					
	Transplant Center	Current Waiting List May 2, 2003	<b>2002 Data</b>		<b>2002 Transplant Procedures</b>
			<b>Additions</b>	<b>Removals</b>	
<b>LIVER</b>					
	Georgetown University Med Center	280	160	92	51
	INOVA Fairfax Hospital	77	45	71	18
<b>HEART</b>					
	Childrens National Med Center	2	6	7	0
	INOVA Fairfax Hospital	10	15	18	15
	Washington Hospital Center	5	11	10	5
<b>HEART LUNG</b>					
	INOVA Fairfax Hospital	0	0	0	0
<b>KIDNEY</b>					
	Childrens National Med Center	14	5	6	8
	Georgetown University Med Center	219	130	20	47
	Howard University Hospital	92	17	25	6
	INOVA Fairfax Hospital	364	108	136	102
	Walter Reed Med Cter	123	37	45	39
	Washington Hospital Center	810	225	112	97
<b>LUNG</b>					
	INOVA Fairfax Hospital	22	28	30	21
<b>PANCREAS</b>					
	Georgetown University Med Center	3	1	1	1
	INOVA Fairfax Hospital	27	10	9	6
	Walter Reed Army Med Center	1	0	3	1
	Washington Hospital Center	16	7	6	4
<b>KIDNEY/PANCREAS</b>					
	Georgetown University Med Center	7	9	5	3
	Howard University	0	0	4	0

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	Hospital				
	INOVA Fairfax Hospital	13	10	14	4
	Walter Reed Army Med Center	2	1	3	0
	Washington Hospital Center	77	26	20	9
<b>TOTALS</b>		2,164	851	637	437

Source: [www.optn.org](http://www.optn.org), UNOS database

Transplant performed includes living and deceased donors

All District transplantation centers are required to be members of UNOS and WRTC and to adhere to the guidelines established by UNOS. Transplantation centers conducting bone marrow transplants are required to follow the FACHCT guidelines. It is also expected that transplantation centers will hold unrestricted accreditation from the Joint Commission on Accreditation of Health Care Organizations (JCAHO).

### A. Availability

To promote effective planning for specialized services through a higher standard of quality for organ transplant services, the following availability standards are established:

- Transplantation services capacity in the District of Columbia and the surrounding metropolitan area should be sufficient to meet the needs of all eligible District and metropolitan area residents, as well as patients referred throughout the region.
  - Where organ transplantation services are not now available and if the area facilities meet the eligibility requirements, area facilities should be encouraged to establish services to meet the needs projected in this area.
  - Facilities requesting expansion of transplant services must meet the guidelines established by UNOS and Medicare requirements and complete the District's CON process.
  - Facilities are expected to meet annual minimum volume requirements to ensure a high standard of quality for organ and tissue transplant services.
  - Facilities requesting expansion of transplant services must demonstrate that they have successful and active organ and tissue recovery programs established within the institutions. This includes full compliance with all Medicare regulations relating to organ and tissue recovery, establishment of non-heart beating donor programs, and on-going programs that promote organ and tissue donation awareness for patients and staff. All organ and tissue donation potential within the institution should be properly identified and referred to the WRTC in a timely manner and all family

discussions surrounding organ and tissue donation should be conducted by WRTC with the support and cooperation of the facility.

- Facilities participating in experimental transplantation services may be permitted to do so, provided that appropriate peer review, data gathering, and analysis and reporting requirements are followed.
- Transplantation services offered in the District should not reduce the availability of needed acute and tertiary level of services to metropolitan area residents.

### **1. *Minimum Volumes***

There is substantial evidence that volume of complex medical and surgical procedures correlates with procedure outcome: better results are observed in centers treating higher volumes of patients. Proliferation of transplant programs may result in an inappropriate dilution of experience and expertise given the restricted supply of organs and tissue for transplantation. Also, the potential for innovations and advancements in surgical techniques, technology, and treatment; the need for ongoing clinical research; and the efficient use of resources (including appropriately trained medical and support staff) require high patient volumes for all types of transplant programs.

Using Medicare volume criteria, each transplant center must achieve the minimum volume of services to qualify for Medicare approval. These are the minimum volumes needed to maintain the entire transplant team's commitment and skills to ensure that procedures are of appropriate quality and safety. The minimum numbers shown in Table 9 are 30 for kidney transplant programs, 15 for all other solid organ transplant programs (liver, pancreas, heart, lung, and heart-lung), and 10 for autologous and allogeneic hematopoietic stem cell transplant programs. Heart-lung transplant procedures may be counted with heart transplants and lung transplants towards the minimum and threshold volume requirements for heart-lung programs.

The applicant must demonstrate that the proposed program can retain sufficient patients to meet the minimum start-up volumes shown in Table 5 within 36 months of initiation of the program. As a condition of approval, the applicant must accept a requirement that it will achieve minimum volumes by the end of the third year of operation and maintain the minimum volume requirements annually thereafter. In the event a transplant center submits a CON for intestine/small bowel transplantation, the minimum number will be 12 by the third year of operation. These numbers are consistent with the Centers for Medicare and Health Care Financing Administration, UNOS, and FAHCT.

High volumes are generally associated with better outcomes through the greater expertise and proficiency of the transplant team. The DOH will not accept a program to operate that is consistently below minimum volumes.

### **2. *Threshold Volumes***

Threshold volumes are intended to be a guide for measuring adverse impact on existing programs when considering the development of additional transplant program capacity. The threshold volumes should not be considered an upper limit on optimal or efficient utilization. In 1999, UNOS reported that the 12 largest liver transplant programs in the country each performed a minimum of 89 liver transplants, the 12 largest kidney transplant programs each performed a minimum of 142 transplants, the 12 largest heart transplant centers each performed a minimum of 33 heart transplants, and the 12 largest pancreas transplant program each performed a minimum of seven pancreas transplants.

Recommended threshold volumes, as shown in Table 9, are 50 for kidney transplant programs, 20 for all other solid organ transplant programs, 20 for autologous transplant programs, and 40 for allogeneic programs. A new organ transplant program will be considered for approval only if existing programs can maintain the threshold volume as a result of the new program. In the event that the annual availability of the number of organ donations limits the program's ability to maintain threshold volumes, each transplant program will be expected to maintain minimum threshold volumes.

### **3. *Pediatric Organ Transplantation Services***

In children, transplantation is sometimes the only option for some diseases and conditions, such as biliary atresia and cardiomyopathy. The number of transplants in children is small, and pediatric transplantation is a very specialized program. Pediatric transplant cases will be limited to a pediatric center of excellence to ensure the best possible outcomes.

### **4. *Wait Times***

UNOS developed a method to determine the number of persons projected to receive a transplant. The projection of the number of persons to receive transplants is based on median waiting time (MWT), which is the estimated number of days until at least 50 percent of new registrants have been transplanted. Among the factors affecting waiting time are the shortage of organs; biologic issues such as blood type and body size of donors and recipients, PRA, immunological factors, and medical urgency status (for liver and heart); donation rates within an area; donation request and consent procedures at OPOs; and patient registration and organ acceptance practices at transplant centers. Confidence limits are used with MWT; confidence limits represent a range of days in which the median is expected to fall. For example, the MWT in 1999 for heart registrants ages 18-34 was 176 days. The 95 percent confidence limits for this group were 129 (lower limit) and 235 (upper limit). This means that one can be 95 percent confident that half of the heart registrants ages 18-34 were transplanted between 129 and 235 days. Confidence limits show the variable waiting times for different groups of patients. A narrow range between the lower and upper limit means there is less variability in waiting time while a broad range indicates greater variability. This can be helpful to patients in



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that it gives them a better idea of the range of waiting time to expect. Confidence limits are presented in the median waiting timetables.

**Table 9. Recommendations for Organ Minimum Volumes  
and Threshold Volumes for 2003**

<b>Transplant Program</b>	<b>Minimum Annual Volume Requirements</b>	<b>Threshold Volume Requirements</b>
Kidney	30	50
Liver	15	20
Pancreas	15	20
Intestine/Small Bowel	15	20
Heart	15	20
Lung, Heart/Lung	15	20
Hematopoietic Stem Cell (bone marrow, peripheral blood):		
Autologous	10	20
Allogeneic	10	40
Islet Cells, Hepatocytes, and Others	To be determined on a case-by-case basis, based on the best information available at the time of the CON application.	

### **B. Accessibility**

The accessibility standards for transplantation services are as follows:

- Transplantation services offered by local hospitals will be open to any practicing physician for referral, with metropolitan area residents given priority for transplants.
- Organ transplant programs must be open 24 hours per day for organ donation and transplantation with capacity for laboratory and auxiliary services to be available on a 24-hour basis.
- Transplantation services should be accessible to all area residents regardless of their ability to pay.
- No person may be denied services on the basis of race, creed, or color.

Given the existence of transplantation capacity in the metropolitan area, it is unnecessary to specify a drive time.

### **C. Continuity**

Continuity of care for all patients affected by the organ and tissue donation and transplant will be a component of the transplantation program. The services that are expected to be offered and/or coordinated include physician and surgeon services, home health services, physical therapy, occupational therapy, nutrition, prescription drugs, counseling/therapy, transportation, lodging, meals on wheels, patient education related to self-care and daily activities, and vocational education, as needed, as well as appropriate social services. Each patient is expected to have a comprehensive treatment plan that addresses the biopsychosocial needs of the patient prior to and post transplant and includes patient and family/caregiver active participation in and agreement with the components of the plan.

Transplant centers will provide information and assist patients in securing recommended services and supplemental coverage for prescription drugs. In addition, each organ transplant center will provide information on Medicaid and Medicare eligibility and assist patients in the application process. Transplant centers will annually submit a summary of services recommended, provided, and coordinated for each patient receiving an organ transplant.

### **D. Quality**

The standards and criteria for quality are discussed below.

UNOS bylaws for transplant programs have three major components:

- Transplant program must use a laboratory that meets UNOS standards for histocompatibility testing.
- Transplant programs must have letters of agreement or contracts with the local OPO.
- Each transplant program must identify a UNOS-qualified primary surgeon and physician. The program director, in conjunction with the primary surgeon and physician, must provide written documentation that 100 percent medical and surgical coverage is provided by individuals credentialed by the institution to provide transplant service for the program. If there is a key change in personnel, the transplant center must include a report from the hospital's credentialing committee that the individual's state licensing, board certification, training, and transplant CMEs are all up to date, and affirm that the individual is currently a member in good standing.

In addition, UNOS requires that the transplant program must be located in a teaching or teaching-affiliated hospital - defined as a hospital that maintains a minimum of 200 licensed beds; has a full residency and fellowship training program that is fully accredited by the Accreditation for Graduate Medical Education with training programs appropriate to the type of transplant program offered; has 24-hour on-site physician coverage by residents, fellows, or attendings; and can demonstrate an institutional commitment to, and support for, medical research.

To ensure optimal outcomes of organ and tissue transplant programs, several quality measures based on UNOS certification requirements or FAHCT certification requirements and JCAHO accreditation standards will be enforced. The quality measures include the minimum and threshold volumes as described in the previous section, surgeon and physician credentialing standards, sufficient number of qualified nursing and allied professional staff assigned to the transplant team, formal quality improvement program, as well as compliance with other UNOS certification requirements and JCAHO standards.

UNOS, FAHCT, and JCAHO are industry-recognized and accepted organizational bodies that have established processes to effectively evaluate the services provided by the transplant centers. For example, UNOS monitors the morality and morbidity of the patient and the graft (organ). The patient receives a heart transplant and dies five years later from another cause. The graft is considered successful for that period of time. Transplant centers that fail to maintain JCAHO accreditation and UNOS or FAHCT certification will be encouraged to withdraw from providing transplantation services.

Additionally, each transplant center needs to annually report organ and tissue donation and transplantation utilization; costs related to each procedure; referrals to support services; types of prescription drugs; payor source (including uninsured District residents); type of organ and number of people evaluated for transplant and number placed on waiting list by age, sex, gender, and race; survival rates; and graft survival rates. Annually, transplant centers are also required to submit a summary of public education efforts, the number of patients approached for organ and tissue donation, and the number of consents.

If an approved District transplant program does not perform organ transplants for one year, the facility is expected to submit to DOH a plan to meet the minimum threshold volumes within the next two years.

### **E. Acceptability**

The acceptability standards for transplantation services are as follows:

- Hospitals must maintain an active public education and awareness campaign that seeks to explain the need for organ donation and the methods for making donations. Public education must also stress the availability of transplant services to the public at large and not just for those who can pay.
- Hospitals should give each family a post transplant questionnaire to measure patient and family member satisfaction with the transplant services provided.

### **F. Cost**

Medical costs prior to and post transplant include both medical and nonmedical. Prior to the time of organ transplant, patients may have costs related to hospitalization, physician and surgeon fees, laboratory evaluation and monitoring, pharmaceutical costs, as well as ancillary service costs such as physical therapy, nutrition, counseling/therapy, and emergency services, including emergency transport. Probably the greatest, yet least measurable, costs are those costs related to quality of life and those that impact on the patient's family during the end stage organ disease.

Medical costs include the following:

- Pre-transplant evaluation and testing;
- The hospital stay and surgery;
- Additional hospital stays for complications;
- Follow-up care and testing;
- Anti-rejection and other drugs, which can easily exceed \$8,500 per year;
- Fees for surgeons, physicians, radiologist, and anesthesiologist;
- Fees for the recovery (procurement) of the organ from the donor;
- Physical, occupational, and vocational rehabilitation; and,
- Insurance deductibles and copayments.

Nonmedical costs may include the following:

- Transportation to and from the transplant center, before and after transplant;
- Food, lodging, and long distance phone calls for patient and family;
- Child care;
- Lost wages of patient, spouse, or significant other;
- Lodging and meals if transplant center is not located near patient's home; and,

- Air travel to get to the transplant hospital quickly with back-up plans for bad weather.

Transplantation costs may be covered by commercial health insurance plans, or by federal or state programs such as Medicare, Medicaid, or TRICARE (the military form of health insurance). However, each of these payor sources may have restrictions as to the type and amount of services covered as well as at which transplant center the patient may receive services. Therefore, any candidate for transplant must investigate their health benefits coverage or arrange for financing prior to receiving a transplant.

### **1. Medicare**

Medicare, the federal insurance program designed for the disabled and those 65 and older, provides coverage for immunosuppressive medications needed by transplant recipients. Medicare pays for some heart, lung, and liver transplants if the recipients are aged 65 or disabled. Those individuals with heart, lung, and liver transplant costs covered by Medicare will be eligible for indefinite drug coverage, as will kidney transplant recipients who meet age or disability requirements. According to estimates from the Institute of Medicine, more than 34,000 people received extended coverage in 2001, growing to more than 44,500 people in 2004.

Individuals whose Medicare benefit entitlement is based solely on ESRD will continue to receive drug coverage for 36 months after transplant. Thereafter, patients requiring continued prescription drug therapies must either self-pay, have a coinsurance program in place, or apply and be accepted into the state's Medicaid program.

Patients eligible for Medicare who are candidates for organ transplant are required to receive organ transplants from a Medicare-approved transplant program.

### **2. Medicaid**

Medicaid, the largest program providing medical and health-related services to America's poorest people, is a state-federal program whose benefits vary considerably from state to state, as well as within each state over time.

The transplantation service benefits provided by the District's Medicaid program include heart, lung, heart-lung, pancreas, kidney-pancreas, liver, and stem cells.

## **VI. GOALS AND OBJECTIVES**

### **Goal 1:**

**To increase the number of transplants performed.**

### **Objectives:**

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- 1.1 Educate District residents on the availability of organ and tissue transplantation services regardless of race, sex, religion, income status, or payor source.
- 1.2 Develop public education campaign for District businesses related to the HHS Gift of Life Donation Initiative and the Workplace Partnership Program.
- 1.3 Encourage District business coalitions to join the new national Workplace Partnership Life campaign in which employers, unions, and other employee groups join in a nationwide network to promote organ and tissue donation.
- 1.4 Create a donor education program in the District's drivers' education programs, including donor cards that specify tissues to be donated and provide 24 hours access to drivers license donor designation information to the WRTC.
- 1.5 Encourage each transplantation center to develop and participate in a community-wide public education program that includes schools, safety net provider sites, faith-based organizations, and social service agencies.
- 1.6 Annually increase the number of organ and tissue donations by ensuring that all hospitals deaths are promptly referred to WRTC (at the time of death in cases of cardiac or respiratory arrest, and when death is imminent in cases of death by neurological criteria). Additionally, ensure that the donation option is presented by WRTC to all eligible families with the support and cooperation of patient care personnel.
- 1.7 Distribute organ and tissue donation education materials and donor cards to all safety net provider sites.
- 1.8 Distribute organ and tissue donation education materials to businesses, including Latino and Asian businesses and business coalitions.
- 1.9 Establish community education program schedule; speakers will represent each of the District's transplant centers.
- 1.10 Include information on organ and tissue donation information on the District of Columbia website.

### **Goal 2:**

**To ensure that all transplantation programs provide the highest quality outcomes for organ and tissue transplantation services.**

### **Objectives:**

- 2.1 Monitor each District of Columbia transplant program to ensure that they meet the minimum volume thresholds for organ transplants by 2005.

2.2 Increase outreach efforts at transplant centers for organ and tissue donation to meet minimum volume requirements.

2.3 Annually perform minimum number of transplants as required by Department of Licensing and Regulations.

**Goal 3:**

**To encourage all stem cell/bone marrow transplant centers to achieve FAHCT accreditation.**

**Objectives:**

3.1 Monitor each District of Columbia hospital providing stem cell/bone marrow transplant services to ensure that they secure and maintain accreditation from FAHCT by 2003.

3.2 Monitor each District facility providing stem cell/bone marrow transplantation services to ensure that they seek application for accreditation by FAHCT by 2003.

3.3 Monitor all facilities that are FAHCT-accredited to ensure that they continue to facilities maintain accreditation status.

## VII. APPENDICES

**Table A- 1. Summary History of Organ Transplants**

Heart	1967 – first human heart transplant 1981 – First successful heart-lung transplant 1982 – First artificial heart – recipient lived 112 days after transplant. 1984 – First baboon-to-human heart transplant – recipient lived 20 days following her xenotransplant.
Intestines	1960s – Small intestine transplants are first attempted in humans 1980s – first successful small intestine transplants occur. 1988 – First successful live-small intestine transplant occurs.
Kidney	1908 – first autologous renal transplant 1933 - First homologous renal transplants from cadavers
Liver	1963 – first human orthotopic liver transplantation
Pancreas	1966 – First pancreas transplant attempted 1966-1977 – 60 transplants attempted, only 2 functioned for more than 1 year. 1978-1985 – Success rate greatly improves to 70% 1986 – Success rate increases to about 90%
Bone Marrow	1950s – Allogenic (person-to-person) attempted in France 1968 – First two unrelated transplants 1973 – First successful unrelated bone marrow transplant 1987 – First search of the American National Marrow Donor Program was successful 1990s – Many advances in bone marrow transplantation occur. Unrelated transplants become more common using umbilical cord blood and peripheral blood stem cells.
Skin	1822 – First successful autograft occurs. 1881 - First temporary skin graft is successful. 1940s – Refrigerated skin first used as temporary dressing for burns 1971 – Cryo-preserved human allografts are introduced. 1980s – Large sheets of test tube skin grown in the laboratory from tiny patches of health skin taken from patient’s body. Serve as permanent grafts for victims of extensive burns.

Source: UNOS Transplant Patient Data Source, 2000, [www.patients.unos.org](http://www.patients.unos.org)



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**Table A- 2. Import Referrals by Organ Type 1999–2000**

Import Referrals by Organ Type		
	2001	2002
Import Kidneys:		
Accepted	34	31
Transplanted	32	29
Import Heart		
Accepted	1	0
Transplanted	1	0
Import Livers		
Accepted	23	15
Transplanted	18	7
Import Pancreata		
Accepted	16	11
Transplanted	7	4
Import Lungs		
Accepted	1	0
Transplanted	1	0

Source: WRTC 2002 OPO Data Report January 2003

**Table A-3. Organ Donation by Hospital,  
Year 2002**

<b>Hospital</b>	<b>Number of Organ Donors</b>
INOVA Fairfax Hospital *	21
Prince George's Community Hospital	9
Washington Hospital Center*	21
Georgetown University Hospital*	2
Children's National Medical Center*	4
Greater Southeast Community Hospital	4
Suburban Hospital	7
Howard University Hospital*	2
George Washington University Hospital	6
Holy Cross Hospital	1
Virginia Hospital Center	4
Potomac Hospital	1
Fair Oaks Hospital	1
National Naval Medical Center	1
Washington Adventist Hospital	1
Montgomery General Hospital	2

Source: WRTC 2002 OPO Data Report January 2003

\* Denotes Facilities with Transplantation Programs

Note: One donor can donate multiple organs.

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**Table A-4. Diagnoses/Reasons for Organ Transplantation**

<b>Heart Diagnosis Categories</b>	<b>Heart Diagnoses</b>
Cardiomyopathy	Dilated myopathy: Idiopathic Dilated myopathy: Myocarditis Dilate myopathy: Other specify Dilate myopathy: Post partum Dilate myopathy: Familial Dilate myopathy: Adriamycin Dilate myopathy: Viral Dilate myopathy: Alcoholic Hypertrophic Cardiomyopathy Restrictive myopathy: Idiopathic Restrictive myopathy: Amyloidosis Restrictive myopathy: Sarcoidosis Restrictive myopathy: Endocardial fibrosis Restrictive myopathy: Other specify Restrictive myopathy: Sec to radiation/chemotherapy
Coronary Artery Disease	Coronary artery disease Dilated myopathy: Ischemia
Congenital heart disease	Congenital heart disease
Valvular heart disease	Valvular heart disease
Retransplant/Graft failure	Heart Re-Tx/GT: Coronary Artery Disease Heart Re-Tx/GT: Other specify Heart Re-Tx/GT: Non-specific Heart Re-Tx/GT: Acute rejection Heart Re-Tx/GT: Hyperacute rejection Heart Re-Tx/GT: Primary failure Heart Re-Tx/GT: Chronic rejection Heart Re-Tx/GT: Restrictive/Constrictive
Other	Cardiac disease: other specify Heart: other specify Cancer
<b>Lung and Heart-Lung Diagnosis Categories</b>	<b>Lung and Heart-Lung Diagnoses</b>
Congenital Disease	Eisenmenger's Syndrome: Arterial Septal Defect Eisenmenger's Syndrome: VSD Eisenmenger's Syndrome: Multi Congenital Anon. Eisenmenger's Syndrome: PDA Eisenmenger's Syndrome: Other specify Congenital: Other specify

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Emphysema/COPD	Emphysema/COPD
Cystic Fibrosis	Cystic Fibrosis
Idiopathic Pulmonary Fibrosis	Idiopathic Pulmonary Fibrosis
Primary Pulmonary Hypertension	Primary Pulmonary Hypertension
Alpha-1-Antitrypsin Deficiency	Alpha-1-Antitrypsin Deficiency
Retransplant/Graft Failure	Lung Re-TX/GT: Obliterative bronchiolitis Lung Re-TX/GT: Other specify Lung Re-TX/GT: Non-specific Lung Re-TX/GT: Acute rejection Lung Re-TX/GT: Primary graft failure Lung Re-TX/GT: Restrictive

<b>Lung and Heart-Lung Diagnosis Categories</b>	<b>Lung and Heart-Lung Diagnoses</b>
Other	Sarcoidosis Lung Disease: other specify Bronchiectasis Pulmonary fibrosis other: specify cause Lymphangioleiomyomatosis Obliterative bronchiolitis: other specify Pulmonary Vascular Disease Occupational lung disease: other specify Inhalation burns/trauma Rheumatoid disease Lung or Heart-Lung: other specify

Source: UNOS Transplant Patient Data Source [www.patients.unos.org](http://www.patients.unos.org)

<b>Intestine Diagnosis</b>
Short Gut Syndrome: Intestinal atresia
Short Gut Syndrome: Necrotizing enterocolitis
Short Gut Syndrome: Intestinal Volvulus Secondary to Malrotation
Short Gut Syndrome: Intestinal Volvulus Secondary to Adhesions
Short Gut Syndrome: Intestinal Volvulus Secondary to Persistent Omphalomesenteric Duct
Short Gut Syndrome: Gastroschisis
Short Gut Syndrome: Massive resection secondary to inflammatory bowel disease (Crohn's Disease)
Short Gut Syndrome: Massive resection secondary to Tumor
Short Gut Syndrome: Massive resection secondary to mesenteric arterial thrombosis or embolus
Short Gut Syndrome: Massive resection secondary to mesenteric venous thrombosis
Short Gut Syndrome: Specify
Short Gut Syndrome: Unspecified

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Functional Bowel Problem: Hirschsprung's disease
Functional Bowel Problem: Neuronal intestinal dysplasia
Functional Bowel Problem: Pseudo-obstruction, neuropathic
Functional Bowel Problem: Pseudo-obstruction, myopathic
Functional Bowel Problem: Protein-losing enteropathy
Functional Bowel Problem: Microvillous inclusion disease
Functional Bowel Problem: Specify
Functional Bowel Problem: Unspecified
Graft failure
Retransplant
Other intestinal Disease
Other, Specify

Source: UNOS Transplant Patient Data Source [www.patients.unos.org](http://www.patients.unos.org)

<b>Liver Diagnosis Categories</b>	<b>Liver Diagnoses</b>
Non-cholestatic Cirrhosis	Laennec's Cirrhosis (Alcoholic) Laennec's Cirrhosis and Postnecrotic Cirrhosis Cirrhosis: Postnecrotic – Type C Cirrhosis: Cryptogenic - Idiopathic Cirrhosis: Postnecrotic –Autoimmune-Lupoi Cirrhosis: Postnecrotic –Type B-Hbsag+ Cirrhosis: Postnecrotic – Type Non A Non B Cirrhosis: Postnecrotic –Type B and C Cirrhosis: Postnecrotic – Other specify Cirrhosis: Drug/Indust Exposure – Other specify Cirrhosis: Postnecrotic - Type B and D Cirrhosis: Postnecrotic – Type A Cirrhosis: Postnecrotic – Type D PNC CAH
Cholestatic Liver Disease/Cirrhosis	Primary Biliary Cirrhosis (PBC) Sec Biliary Cirrhosis: Other specify Sec Biliary Cirrhosis: Caroli's Disease Sec Biliary Cirrhosis: Choledochol Cyst Choles Liver Disease: Other specify PSC: Other specify PSC: Ulcerative Colitis PSC: No bowel disease PSC: Crohn's disease
Biliary Atresia	Biliary Atresia: Other specify Biliary Atresia: Extrahepatic Biliary Atresia: Alagille's Syndrome Biliary Atresia: Hyoplasia

## Transplant Services – Preliminary Draft

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Acute Hepatic Necrosis (AHN)	AHN: Etiology unknown AHN: Type B-Hbsag+ AHN: Drug Other Specify AHN: Non-A Non-B AHN: Type C AHN: Type A AHN: Other specify AHN: Type B and C AHN: Type D Hepatitis: Chronic or Acute Hepatitis: Chronic or Acute
Metabolic Diseases (Metdis)	Metdis: Alpha-1-Antitrypsin Defic A-1-A MetdisWilson's Disease Metdis: Hemochromatosis-Hemosiderosis Metdis: Other specify Metdis: Trysinemia Metdis: Primary oxalosis/Oxaluria-Hyper Metdis Gly Stor Dis Type (GSD-II) Metdis: Glyc Stor Dis Type I (GSD-I) Metdis: Hyperlipidemia-II-Homozygous Hy

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<b>Liver Diagnosis Categories</b>	<b>Liver Diagnoses</b>
Malignant Neoplasms	PLM: Hepatoma-Hepatocellular Carcinoma PLM: Hepatoma (HCC) and Cirrhosis PLM: Cholangiocarcinoma (CH-CA) PLM: Hepatoblastoma (HBL) PLM: Hemangioendothelioma-hemangiosarcoma PLM: Other specify PLM: Fibromellar (FL-HC) Bile Duct Cancer (Cholangioma-Biliary Tr) Secondary Hepatic Malignancy – Other specify
Other	Cystic Fibrosis Other Specify Budd-Chiari Syndrome TPN/Hyperalimentation – Ind Liver Disease Neonatal Hepatitis – Other specify Congenital Hepatic Fibrosis Familial Cholestasis: Other specify Familial Cholestasis: Byler's Disease Trauma: other specify Graft vs. Host Dis Sec to Non-Li Tx Chronic or Acute Benign tumor: Polycystic liver disease Benign tumor: Other specify Benign tumor: Hepatic adenoma

Source: UNOS Transplant Patient Datasource

<b>Pancreas Diagnosis</b>
Retransplant/graft failure
Diabetes Mellitus – Type 1
Diabetes Mellitus – Type II
Diabetes Secondary to Chronic Pancreatitis without pancreatectomy
Diabetes Secondary to Cystic Fibrosis without pancreatectomy
Pancreatic cancer
Bile duct cancer
Other cancers
Pancreatectomy prior to Pancreas Transplant
Other specify

Source: UNOS Transplant Patient Datasource

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<b>Kidney Diagnosis Categories</b>	<b>Kidney Diagnoses</b>
Glomerular Diseases	Anti-GBM Chronic Glomerulonephritis: Unspecified Chronic Glomerulosclerosis: Unspecified Focal Glomerularsclerosis IDIO/Posy-Inf Crescentic Glomerulonephritis IGA Nephropathy Hemolytic Uremic Syndrome Membranous Glomerulonephritis IGA Nephropathy Hemolytic Uremic Syndrome Membranous Glomerulonephritis Mesangio-Capillary 1 Glomerulonephritis Mesangio-Capillary 2 Glomerulonephritis Systemic Lupus Erthematosus Alport's syndrome Amyloidosis Membranous nephropathy Goodpasture's Syndrome Henoch-Schoenlein Purpura Sickle Cell Anemia Wegeners Granulomatosis
Diabetes	Diabetes: Type 1 Insulin Dep/Juvenile Onset Diabetes: Type II Insulin Dep/Adult Onset Diabetes: Type I Non-insulin Dep/Juvenile Onset Diabetes: Type I Non-insulin Dep/Adult Onset
Polycystic kidneys	Polycystic kidneys
Hypertensive Nephrosclerosis	Hypertensive nephrosclerosis
Renovascular & Other vascular diseases	Chronic nephrosclerosis: unspecified Malignant hypertension Polyarteritis Progressive systemic sclerosis Renal artery thrombosis Scleroderma
Congenital, Rare Familial & Metabolic Disorders	Congenital obstructive uropathy Cystinosis Fabry's disease Hypoplasia/Dysplasia/Dysgenesis/Agensis Medullary Cystic Disease Nephrophthisis Prune Belly Syndrome



## Transplant Services – Preliminary Draft

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Neoplasms	Incidental carcinoma Lymphoma Myeloma Renal Cell Carcinoma Wilms Tumor
ReTransplant/Graft Failure	Retransplant/Graft Failure
Other	Other specify: Rheumatoid arthritis Familial Nephropathy

Source: UNOS Transplant Patient Datasource

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### IX. GLOSSARY

**ACUTE REJECTION:** The body's attempt to destroy the transplanted organ, which usually occurs in the first year after transplant.

**ADVERSE REACTION:** An unintended effect from a drug.

**ALLOCATION:** The system of ensuring that organs and tissues are distributed fairly to patients who are in need of a transplant.

**ALLOGRAFT:** An organ or tissue that is transplanted from one person to another of the same species: i.e. human-to-human. Example: a transplanted kidney.

**ANTIBODY:** A protein substance made by the body's immune system in response to a foreign substance, for example a previous transplanted organ, blood transfusion, virus or pregnancy. Because the antibodies attack the transplanted organ, transplant patients must take powerful anti-rejection drugs.

**ANTIGEN:** A foreign substance, such as a transplanted organ, that triggers the body to try to destroy it. This response may be the production of antibodies, which try to destroy the antigen. (the transplanted organ).

**ANTI-REJECTION DRUGS (IMMUNOSUPPRESSIVE DRUGS):** Drugs that are taken to help the body accept the transplanted organ.

**BENEFICIARY:** The person who receives the benefits of an insurance policy.

**BENEFITS:** Paid for services of an insurance policy.

**BLOOD VESSELS:** The veins, arteries and capillaries through which blood flows. Blood vessels can be donated and transplanted.

**BRAIN DEATH:** When the brain has permanently stopped working, as determined by the physician. Artificial support systems (machines may maintain functions such as heartbeat and breathing for a few days, but not permanently. Donor organs are usually taken from people who have been declared "brain dead".

**CADAVER:** A dead body.

**CADAVERIC:** Refers to things about or relating to a dead body.

**CADAVERIC DONOR:** A person who has been declared "brain dead" and whose family has offered one or more organs or tissues to be used for transplantation.

**CANDIDATE:** A person who is waiting for a transplant.

**CARDIAC:** Having to do with, or referring to, the heart.

**CHRONIC:** Developing slowly and lasting for a long time, or the rest of the patient's life. Example: Kidney failure.

**CHRONIC REJECTION:** Slow failure of the transplanted organ.

**CIRRHOSIS:** A disease of the liver in which normal, healthy tissue is replaced with nonfunctioning tissue, and healthy, functioning liver cells are lost; usually occurs when there is a lack of adequate nutrition, infection, or damage caused by alcohol abuse.

**COINSURANCE:** A percentage of money that you must pay toward a service that your insurance will pay. A very typical amount is 20%; you pay 20% of the doctor's bill and your insurance pays the other 80%.

**CO-PAYMENT (CO-PAY):** A flat fee that a person pays for health care services in addition to what the insurance company pays. Example - a \$10 "co-payment" each time you visit your doctor.

**CORTICOSTEROID:** A synthetic hormone, which stops your body's normal reaction to infection and foreign tissue, such as a transplanted organ. Prednisone is a corticosteroid.

**COVERAGE DATE:** The day that your insurance benefits begin.

**COVERED BENEFIT/COVERED SERVICE:** A service or supply that an insurance company will provide payment toward.

**CRITERIA (MEDICAL CRITERIA):** A set of standards or conditions that must be met.

**CYCLOSPORINE.** A drug used to prevent rejection of the transplanted organ by suppressing the body's immune system.

**DEDUCTIBLE:** A fixed amount of money you must pay for covered health care expenses before the insurance company starts to pay. This is usually a yearly amount, such as \$250, \$500, \$1000 or more.

**DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS):** This department of the federal government is responsible for health-related programs and issues. Formally called HEW (the Department of Health, Education and Welfare).

**DEPENDENTS:** Those persons who also receive insurance benefits from the primary insurance card holder, example, spouse and children.

**DIALYSIS:** A mechanical process, which works to correct the balance of fluids and chemicals in the body, and removes wastes from the body when kidneys are failing. (See hemodialysis and peritoneal dialysis).

**DISABILITY (DISABLED):** An injury or illness that keeps a person from working. Some disability insurance policies pay benefits if the person is unable to work.

**DISABILITY DETERMINATION SERVICE:** A state agency that will review eligibility for vocational rehabilitation.

**DISABILITY INSURANCE:** Provides income if illness or injury prevents the person from being able to work for an extended period of time.

**DIVISION OF TRANSPLANTATION (DOT):** The office of the federal government whose principal responsibilities include the management of the Organ procurement and Transplantation Network (OPTN), the Scientific Registry of Transplant Recipients

(SRTR), and the National Marrow Donor Program (NMDN) contracts, public education to increase organ/tissue donation and technical assistance to organ procurement organizations (OPOs).

**DONOR:** Someone from whom an organ or tissue is used for transplantation.

**DONOR CARD:** A card that states the wishes of an organ donor.

**DURABLE POWER OF ATTORNEY:** A legal document in which someone is named to make medical decisions for the individual that is unable to make the decision.

**END STAGE ORGAN DISEASE:** A disease that leads to the permanent failure of an organ.

**END-STAGE RENAL DISEASE/CHRONIC KIDNEY FAILURE (ESRD):** A condition in which the kidneys no longer function and for which the patient needs dialysis or a transplant.

**END STAGE RENAL DISEASE (ESRD) PROGRAM:** Part of the Medicare program that provides people with end stage kidney disease, or renal failure, with medical coverage to help pay for dialysis or transplantation

**EXCLUSION:** Medical services that are not paid by an insurance policy.

**EXPERIMENTAL:** New treatments, procedures or drugs that are being tested. Insurance companies do not usually pay for anything that is considered experimental.

**FEDERALLY MANDATED:** Required by Federal law.

**GENETIC:** Referring to heredity, birth or origin.

**GRAFT:** A transplanted organ or tissue.

**GRAFT SURVIVAL:** The percentage of patients who have functioning transplanted organs (grafts). They are usually given in 1, 3 and 5 years time periods.

**GROUP INSURANCE/GROUP HEALTH INSURANCE:** Typically offered through employers, unions, professional associations, and other organizations. If employer offers insurance it usually pays a portion of the premium.

**HARVEST:** The act of surgically removing an organ or tissue for transplantation; now referred to as "recover" rather than "harvest".

**HEALTH AND HUMAN SERVICES (HHS):** See DHHS.

**HEALTH MAINTENANCE ORGANIZATION (HMO):** An insurance plan where you or your employer pay a fixed monthly fee for services, regardless of the level of care.

**HEMODIALYSIS:** A treatment for kidney failure where the patient's blood is passed through a machine to remove excess fluid and wastes. The procedure usually takes about 3-4 hours per session and is usually done about 3 times per week..

**HEPATIC:** Having to do with, or referring to, the liver.

**HEPATITIS:** Inflammation of the liver; can lead to liver failure..

**HIGH BLOOD PRESSURE (HYPERTENSION):** When the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less able to stretch or have gotten smaller. High blood pressure causes the heart to pump harder to move blood through the body. High blood pressure can cause kidney failure if not treated.

**HLA SYSTEM:** There are three major genetically controlled groups: HLA-A, HLA-B and HLA-DR. In transplantation, the HLA tissue types of the donor and recipient are important in determining whether the transplant will be accepted or rejected. This testing is routinely performed on kidneys and pancreas only.

**HUMAN IMMUNODEFICIENCY VIRUS (HIV):** A virus destroys cells in the immune system, which makes it difficult for the body to fight off toxins, or poisons, and diseases. HIV is the virus that causes AIDS.

**HUMAN LEUKOCYTE ANTIGENS (HLA):** Molecule found on cells in the body that characterizes each person as unique. These antigens are inherited from your parents. In donor-recipient matching, HLA determines whether an organ from one individual will be accepted by another.

**IMMUNE RESPONSE:** The body's natural defense against foreign objects or organisms, such as bacteria, viruses or transplanted organs or tissue.

**IMMUNE SYSTEM:** The organs, tissues, cells, and cell products in your body that work to find and neutralize foreign substances, including bacteria, viruses, and transplanted organs.

**IMMUNOSUPPRESSION:** The artificial suppression of the immune response, usually through drugs, so that the body will not reject a transplanted organ or tissue.

**IMMUNOSUPPRESSIVE:** Relating to the weakening or reducing of your immune system's responses to foreign material; immunosuppressive drugs reduce the immune system's ability to fight a transplanted organ.

**INFORMED CONSENT:** The process of reaching an agreement based on a full understanding of what will take place. Informed consent has components of disclosure, comprehension, competence and voluntary response.

**INPATIENT TREATMENT:** Treatment in the hospital with at least an overnight stay.

**INSURANCE BENEFITS:** Services paid by an insurance company.

**INTENSIVE CARE UNIT (ICU)/CRITICAL CARE UNIT (CCU):** A unit in the hospital that has highly technical and sophisticated monitoring devices and equipment. The staff is specially trained and educated.

**INVESTIGATIONAL:** A drug or procedure that is not yet approved for marketing. Insurance companies normally do not pay for investigational drugs or procedures.

**KIDNEYS:** A pair of organs that remove wastes from your body through the production of urine.

**LEGISLATION:** A group of laws and regulations.

**LEUKOCYTE:** A white blood cell

**LIFETIME MAXIMUM/LIFETIME CAP:** The total amount of money an insurance company will pay out for covered expenses during the beneficiary's lifetime.

**LIVER:** The largest gland in the body, made up of a spongy mass of wedge-shaped lobes. The liver secretes bile, which aids in digestion, helps process proteins, carbohydrates, and fats, and stores substances like vitamins. It also removes wastes from the blood.

**LIVING-RELATED DONOR (LRD):** A family member who donates a kidney, part of a lung, liver or pancreas to another family member. Example: a brother and a sister, or a parent and a child.

**LIVING-UNRELATED DONOR (LUD):** A person who is not related by blood, who donates a kidney, part of a lung, liver, or pancreas to another person (such as a husband and wife).

**MANAGED CARE:** A term used to describe insurance programs that try to control health costs by limiting unnecessary treatment. Health Maintenance Organizations (HMOs), Preferred Provider Organizations (PPOs) and Point-Of-Service (POS) plans and utilization review are all forms of managed care.

**MATCH:** The compatibility between the donor and the recipient. The more closely they match, the greater the chance that the transplant will be successful.

**MEDICAID:** A partnership between the federal government and the individual states to share the cost of providing medical coverage for recipients of welfare programs and allows states to provide the same coverage to low income workers not eligible for welfare. Programs vary greatly from state to state.

**MEDICALLY NECESSARY:** A specific health care service or supply which your insurance company has determined is required for your medical treatment and is also the most efficient and economical way to provide that service or supply.

**MEDICARE:** The program of the federal government that provides hospital and medical insurance, through social security taxes, to people age 65 and over and those who have permanent kidney failure and certain people with disabilities.

**MEDIGAP POLICY (MEDSUPP, MEDICARE SUPPLEMENTARY):** Private insurance that helps cover some of the gaps in Medicare coverage.

**MORTALITY:** Death (mortality rate = death rate)

**MULTIPLE LISTING:** Patient is on the waiting list at more than one transplant center

**NONCOMPLIANCE:** Failure to follow the instructions of the medical team, for example, non-adherence to medicines or failure to keep clinic appointments. Noncompliance can easily lead to the loss of the new organ.



**NATIONAL ORGAN TRANSPLANT ACT (NOTA):** Passed by Congress in 1984, outlawed the sale of human organs and initiated the development of a national system for organ sharing and a scientific registry to collect and report transplant data.

**OPO LOCAL AREA:** Each OPO provides its organ procurement services to the transplant programs in its area. An OPO's local service area can include a portion of a city, a portion of a state or an entire state. When an organ becomes available, the list of potential recipients is generated from the OPO's local service area. If a patient match is not made in that local area, a wider, regional list of patients waiting is generated.

**ORGAN:** A part of the body made up of tissues and cells that enable it to perform a particular function. Transplantable organs are the heart, liver, lungs, kidneys, pancreas, and intestines.

**ORGAN DONATION:** To give an organ, such as a kidney, to someone in need of that organ; or to decide that after a person dies, the family has permission to give the healthy organs to people in need of them.

**ORGAN PRESERVATION:** Donated organs require special methods of preservation to keep them viable between procurement and transplantation. Without preservation, the organ will deteriorate. The length of time organs and tissues can be kept outside the body vary depending on the organ, the preservation fluid and the temperature.

**ORGAN PROCUREMENT:** The removal or retrieval of organs and tissues for transplantation.

**ORGAN PROCUREMENT AND TRANSPLANTATION NETWORK (OPTN):** A function supervised by the Department of Transplantation (DOT), which maintains the national computerized list of patients waiting for organ transplants and a 24 hour-a-day computerized organ placement center to match donor organs to recipients in a fair and efficient manner; this function is performed by UNOS.

**ORGAN PROCUREMENT ORGANIZATION (OPO):** OPOs serve as the vital link between the donor and recipient and are responsible for the identification of donors, and the retrieval, preservation and transportation of organs for transplantation. They are also involved in data follow-up regarding cadaveric organ donors. As a resource to the community they serve, they engage in public education on the critical need for organ donation. Currently, there are 69 OPOs around the country. All are UNOS members.

**OUT OF POCKET EXPENSES:** The portion of health costs that must be paid by the insured person per year, including deductibles, co-payments and co-insurance. After this amount is paid, the insurance company pays benefits at 100%.

**OUTPATIENT CARE (AMBULATORY CARE):** Medical testing or treatment that is done without an overnight hospital stay. Can be done in a hospital setting or a doctor's office.

**PANCREAS:** A long, irregularly shaped gland that lies behind the stomach, and secretes pancreatic juice into the lower end of the stomach that aids in the digestion of proteins,

carbohydrates, and fats. If the pancreas fails, the individual becomes diabetic, and may need to take insulin. The pancreas can be donated and transplanted.

**PANEL REACTIVE ANTIBODY (PRA):** The percentage of cells from a panel of donors with which a potential recipient's blood serum reacts. The more antibodies in the recipient's blood, the more likely the recipient will react against the potential donor. The higher the PRA, the less chance of receiving an organ that will not be rejected. A patient with a PRA of 80% means that they will reject 80% of donor kidneys. Patients with a high PRA have priority on the waiting list.

**POOL:** A group of people.

**POTENTIAL RECIPIENT:** A person who is waiting for a transplant.

**PRE-AUTHORIZATION (PRE-CERTIFICATION):** The process of notifying and getting approval from your insurance company before you proceed with an elective (non-emergency) medical procedure. If insurance plan requires pre-certification, and if obtained, the share of the cost will be higher.

**PRE-EXISTING CONDITION:** Any disease, illness, sickness, or condition, which was diagnosed or treated by a Provider within 12 months before the start date of an insurance coverage. Also, anything that caused symptoms in those 12 months that would cause most people to seek medical care.

**PREFERRED PROVIDER ORGANIZATION (PPO):** A group of hospitals or physicians who have made a contract with a particular insurance company to provide care to their members, usually at a discounted charge. If you have a PPO type insurance plan, your share of the cost is usually lower if you use one of these designated providers.

**PREMIUM:** Amount paid to an insurance company for providing medical or disability coverage under a contract.

**PRIVATE HEALTH PLAN:** An insurance policy bought by an individual, not through an employer.

**PROCUREMENT:** The act of recovering a donated organ or tissue.

**PULMONARY:** having to do with, or referring to, the lungs.

**RACE:** For UNOS purposes: Alaskan Native, American Indian, Asian, Black or African American, Native Hawaiian, Pacific Islander, and White.

**RECIPIENT:** A person who has received a transplant.

**RECOVERY (ORGAN):** The surgical procedure of taking an organ from a donor.

**REJECTION:** Rejection occurs when the body tries to destroy a transplanted organ or tissue because it sees the organ or tissue as a foreign object and produces antibodies to destroy it. Anti-rejection (immunosuppressive) drugs help prevent rejection.

**RENAL:** Having to do with, or referring to, the kidneys.

**Required request:** Hospitals must tell the families of suitable donors that their loved one's organs and tissues can be used for transplant. This law is expected to increase the number of donated organs and tissues for transplantation by giving more people the opportunity to donate.

**RETRANSPLANTATION:** Due to rejection or failure of a transplanted organ, some patients receive another transplant after having returned to the waiting list.

**RETRIEVAL:** The surgical procedure of taking an organ from a donor.

**RISK POOLS:** A state-created, nonprofit association that does not require tax dollars for its operational purposes. The risk pools are a temporary stopping place for individuals who are denied health insurance, for medical reasons. Risk pools often help individuals who, because of their physical condition are unable to purchase health insurance at any price.

**SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS (SRTR):** UNOS maintains the SRTR, which includes information on all recipients of kidney, heart, liver, heart-lung, lung and pancreas transplant since October 1, 1987. The Registry also tracks all transplant patients from the time of transplant through hospital discharge, and then annually, until graft failure or death.

**SECOND OPINION:** A medical opinion provided by a second physician or medical expert, when one physician provides a diagnosis or recommends surgery to an individual.

**SOCIAL SECURITY ADMINISTRATION:** A federal government program, best known for its retirement benefits. The Social Security Administration also administers disability benefits. Your salary and the number of years you have been covered under this program determine how much you can receive in monthly payments.

**SPEND DOWN:** For disabled people who have higher incomes, but cannot pay their medical bills. Under this program, a person pays a part of their monthly medical expenses (the spend down), then Medicaid will step in and pay the rest. Eligibility is determined on a case-by-case basis.

**STATUS:** A code number used to indicate the degree of medical urgency for patients awaiting heart or liver transplants. Example: Status 1, Status 2, or Status 3.

**SUPPLEMENTAL POLICY (MEDIGAP POLICY):** Offered by private insurance companies, not the government. These policies are designed to pay for some of the costs that Medicare does not cover. These policies have limited coverage for medicine costs.

**SURVIVAL RATES:** Survival rates indicate what percentage of patients are alive or grafts (organs) are still functioning after a certain amount of time. Survival rates are used in developing UNOS policy. Because survival rates improve with technological and scientific advances, developing policies that reflect and respond to these advances will also improve survival rates.

**TERMINATION OF BENEFITS:** Health insurance benefits will stop when the individual has reached the lifetime maximum amount, or when the individual is no longer eligible for the plan due to non-payment of premiums or having left or lost a job.

**THORACIC:** Referring to the heart, lungs and chest.

**TISSUE:** An organization of a great many similar cells that perform a special function. Examples of tissues that can be transplanted are blood, bones, bone marrow, corneas, heart valves, ligaments, saphenous veins, and tendons.

**TISSUE TYPING:** A blood test done to evaluate how closely the tissues of the donor match those of the recipient (done before the transplant). Done on all donors and recipients in kidney transplants to help match the donor to the most suitable recipient.

**TRANSPLANT, TRANSPLANTATION:** To transfer a section of tissue or complete organ from its original position to a new position. For instance, transferring a healthy organ from one person's body to the body of a person in need of that organ.

**U.S. SCIENTIFIC REGISTRY OF TRANSPLANT RECIPIENTS (SRTR):** A database of post transplant information. Follow-up data on every transplant are used to track transplant center performance, transplant success rates and medical issues impacting transplant recipients. Under contract with the Health Resources and Services Administration (HRSA), UNOS facilitates the collection, tracking and reporting of transplant recipient and donor data.

**UNOS:** United Network for Organ Sharing.

**USUAL AND CUSTOMARY (U&C) FEE:** The fee that providers of similar training and experience charge for a service in a particular geographical area.

**VENTILATOR:** A machine that "breathes" for a patient when the patient's body is not able to breathe on its own.

**WAITING LIST (WAITING POOL):** After evaluation by the transplant physician, a patient is added to the national waiting list by the transplant center. Lists are specific to both geographic area and organ type: heart, lung, kidney, liver, pancreas, intestine, heart-lung, and kidney-pancreas. Each time a donor organ becomes available, the UNOS computer generates a list of potential recipients based on factors that include genetic similarity, blood type, organ size, medical urgency and time on the waiting list. Through this process, a "new" list is generated each time an organ becomes available that best "matches" a patient to a donated organ.

**WAITING PERIOD:** A period of time when a person is not covered by insurance for a particular problem, such as a pre-existing condition.

**XENOGRAFT:** An organ or tissue procured from an animal for transplantation into a human.

**XENOTRANSPLANTATION:** Transplantation of an animal organ into a human. Although xenotransplantation is highly experimental, many scientists view it as an eventual solution to the shortage of human organs.